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Committee Secretariat
Health Select Committee
Parliament Buildings
Wellington

Submission: Inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders

On behalf of the Neurological Alliance of NZ (the Alliance) thank you for the opportunity to comment on the above enquiry. The kaupapa of this inquiry is important because our health and disability systems are ill-prepared to support the current and growing numbers of people affected by neurological conditions.

The Alliance does wishes to be heard by the Health Committee. Please note that several of our members are making separate submissions to provide the Committee with more specific information.

Who are we?

The Alliance was established in 1999 to provide a forum for organisations representing neurological conditions to work together and make representations on matters of common interest. All members have a desire to promote community awareness of neurological conditions and to see that the needs of people with neurological conditions are met by Government funded services across the care continuum.

The Alliance represents twenty non-governmental organisations that provide practical support, care, and advocacy for people (and their families/carers) affected by neurological conditions.

A list of our twenty member organisations can be found at the end of this letter.

What are our priorities?

In 2023 the Alliance surveyed our members to inform the setting of joint priorities. These are to:

1) Address health workforce shortages to speed up diagnosis and treatment of neurological conditions
2) Increase funding for pharmaceutical treatment to improve quality of life
3) Increase funding for community-based care and support services; and
4) Improve data collection on neurological conditions.

Priorities 1 and 3 align with parts of the Terms of Reference for this submission and we will provide the committee with insights from our member survey.

Priority 1 - Workforce

Health workforce shortages are increasingly causing delays in diagnosis and treatment. There are shortages of neurologists, specialist nurses, physiotherapists, occupational therapists, psychotherapists, speech language therapists and home-carers.

Non-Government Organisations (NGOs) also face challenges with recruitment and retention of specialist staff, as underfunding of the not-for-profit sector by Government undermines their ability to attract and retain staff within the wider health sector.

These shortages are affecting people with neurological conditions of all ages and are particularly distressing for people whose conditions have no cure and result in quick deterioration such as Motor Neurone Disease and other rare neurological disorders.

Priority 3 – Community-based care and support

Many people with neurological conditions such as Alzheimer's and other dementia, stroke, and Parkinson's live at home independently or with the support of family whānau carers. They rely on services and programmes delivered in their communities.

Shortfalls in health funding for community-based workers and historical underfunding of the sector means that the Alliance members can only reach a fraction of the people who need support. Family whānau carers are also burnt out and struggling to access respite care.

Why are neurological conditions important?

Globally neurological conditions are now the leading cause of ill health and disability and are the top contributor to the global burden of disease.[1]

In Aoteoroa New Zealand the Alliance estimates that 1 in 3 New Zealanders will be affected by a neurological condition at some point in their lifetime.[2] According to mortality data, one in five deaths in Aotearoa are caused by a neurological condition.[3]

Why are neurological conditions increasing?

The rapid growth in neurological conditions over the last 30 years, in Aoteoroa New Zealand and globally, has been driven by population growth, an aging population, people living longer

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[1] https://www.healthdata.org/news-events/newsroom/news-releases/lancet-neurology-neurological-conditions-now-leading-cause-ill

[2] This reflects the data from the Global Burden of Disease for the time year period ending 2019.

[3] https://www.tewhatuora.govt.nz/our-health-system/data-and-statistics/mortality-web-tool/

with conditions and increasing exposure to environmental and metabolic / lifestyle risk factors.

Neurological conditions place a significant burden on health and disability systems, particularly for older people who experience greater incidence of disability for long term conditions such as Stroke, Parkinson’s, Alzheimer’s, and other dementias.

What do these trends mean for this inquiry?

The rapid increase in the number of people with neurological disorders mean that Government needs to *increase its investment in support services across the care continuum.* While the terms of reference for the inquiry relates to the adequacy of the aged care sector, the number of people experiencing neurological cognitive disorders is not confined to those aged over 65 years.

Key messages

- Many people with neurological conditions live at home and are reliant on community-based services to live as independently and well as possible.
- The lack of services for people experiencing early onset neurological conditions is exacerbating inequities for some populations groups that experience onset earlier – for example Māori and Pacific people experience stroke 15 years younger than European.
- Many people with neurological conditions such as Alzheimer’s and other dementia, Parkinson’s and Stroke are falling through the gaps because there is under-investment in services for people aged under and over 65 years.
- The prevalence of some neurological conditions increases with age so demand for services is going to keep increasing, this includes increasing demand for better support for carers.
- The age of onset for some neurological conditions is getting younger so the Government funding criteria to access services across the continuum of care needs to be adjusted to meet need.

The next section contains examples of comments from a selection of Alliance members relevant to this inquiry’s Terms of Reference. Please note that fuller detail will be provided in separate submissions from Dementia NZ and Alzheimer's NZ.

Parkinson’s NZ

- **Appropriate services for people with neurological cognitive disorders across the care continuum including from home and community care to residential care, to palliative care.**

In Aotearoa New Zealand we have an absence of well-developed policies and lack a coordinated approach to the provision of integrated specialist nursing care (unlike the United Kingdom). This is particularly noticeable in regional and rural areas.

The UK’s integrated health system has enabled the development of a strong policy framework and national scope of practice for specialist Parkinson’s disease nurses because of cooperation between government and nursing (Abendroth, Lutz, & Young, 2012)

International guidelines recommend a person with Parkinson's is cared for by a specialist (Neurologist/Geriatrician). They recommend access to a Parkinson's nurse (with a case load of no more than 300 People with Parkinsons/ FTE). It is recommended in international guidelines that people with Parkinsons are reviewed by their specialist every 6 months. This is rarely the case. The Aotearoa New Zealand system does not support clinicians to meet these best practice guidelines.

- **Process for diagnosing neurological cognitive disorders and the effects of diagnoses on funding and treatment.**

By the time of diagnosis, individuals with Parkinson’s are often already at an advanced stage of disease and disability, have reduced quality of life, and require complex management. Due to the gradual decline in functional status with disease progression, those over the age of 65 diagnosed with Parkinson’s are likely to live in long-term care supported by healthcare professionals. While there are no reliable reported figures documenting an exact figure of people living in residential care settings in Aotearoa New Zealand with Parkinson’s an American-based study suggested a figure of 5-10%[4].

- **The funding model, amount of funding available, including best practice and international examples of funding models.**
- **Resources available and the ability for the health system to provide appropriate care and what support enables 'aging in place', including for priority populations.**

90% of referrals to Parkinson’s NZ are received directly from Te Whatu Ora but less than 11% of our funding is received from government sources.

Te Whatu Ora relies heavily on Parkinson's NZ to bridge the gap and help people to age in place. Research conducted by Parkinson's UK has found:

> *"Parkinson’s nurses can enable savings to be made across health and social care services. Timely nurse input results in fewer emergency hospital admissions, reduced hospital length of stay, fewer falls, and improved mobility and independence of people with Parkinson’s.*[5]

Closer to home this model is employed by the Health Department of Western Australia who fund Parkinson's nurses via their local Parkinson's organisation.

- **Projections for future needs for people with neurological cognitive disorders.**

Incidence of disability secondary to Parkinson’s disease is increasing faster globally than any other neurological condition[6]

Over 12,000 New Zealanders (or 1 in every 500 people in the general population and 1 in 100 people over 65) have Parkinson’s. The incidence of Parkinson’s is increasing, and researchers predict the number of people with Parkinson’s will increase to 17,500 by 2035 and grow to 24,000 by 2068.

The demand for services from Parkinson's NZ has increased by 30% in the past four years. We received 370 referrals in the past 6 months alone. There is a growing demand for our services from Te Whatu Ora, the primary care sector and other organisations involved in the care of people with Parkinson’s.

Alzheimers NZ and Dementia NZ

Dementia is one of the most significant health and social challenges facing the country and will worsen as the population ages, placing additional pressure on an already struggling health system. Currently an estimated 75,000 people are living with dementia, projected to increase to 170,000 by 2025.[7]

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[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10885076/

[5] https://www.parkinsons.org.uk/sites/default/files/2022-07/Pump%20Priming%20Nurse%20Posts%20-%202022%20and%20beyond.pdf

[6] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10885076/

[7] Mau E, (2020) Dementia Economic Impact Report, University of Auckland

Most people with dementia live at home for most of their time after receiving the diagnosis but many face significant challenges in accessing the health services they need. Of the estimated 75,000 New Zealanders living with dementia, around 30,000 are missing out on essential community-based dementia support due to lack of funding.

An evidence-based Dementia Mate Wareware Action Plan 2020-2025 has been developed specifically to address the pending dementia crisis. This plan needs to be funded.

To quantify the cost of a comprehensive community-based dementia mate wareware service Alzheimers NZ and Dementia NZ have produced a business case - ‘Fair funding for community-based dementia services.’ This case offers considerable benefit to Government by supporting a shift away from high-cost residential and hospital services to community delivered services, thus reducing the impact of dementia on the health system, providing economic benefit, and building a sustainable dementia sector for the future. This business case was provided to Health NZ/Te Whatu Ora and Ministers in late 2023.

There is currently a short-term focus on addressing the long-term challenge of dementia mate wareware in Aotearoa New Zealand. No decision has been made to fund and implement the Action Plan in its entirety, and nothing is being done to address the unmet need or to prepare for the predicted rapid growth in those with dementia. This is despite the compelling evidence that urgent actions are needed to mitigate the very considerable risks dementia poses.

Stroke Foundation NZ

Stroke is a leading cause of adult disability in Aotearoa New Zealand[8] and the second leading cause of death in Aotearoa New Zealand.[9]

At least 12,000 strokes and TIAs (Transient Ischaemic Attacks or mini strokes) are experienced every year.[10] That equates to 33 strokes and TIAs every day, more than one every hour. The prevalence of stroke is 89,000 people[11] and is number is projected to keep rising.

This will place significant pressure on health and disability systems. NZIER estimated the annual economic cost of stroke in 2020 at $1.1b, increasing to $1.7b by 2038.[12]

25-30% of people who experience stroke are aged under 65 years and Māori and Pacific people are disproportionately represented. Longitudinal research by the National Institute for Stroke and Applied Neuroscience (NISAN) at the Auckland University of Technology found that has been a significant increase in the number of young people having strokes in the last twenty years – up by 9% since 2002.

Moreover, Māori and Pacific people experience stroke, on average 15 years earlier than European New Zealanders, have greater rates of recurrent stroke and experience greater levels of disability after stroke.

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[8] NZ Health Survey 2022/23

[9] Ministry of Health Mortality Web Tool (2021 latest data). Note stroke is second after ischemic heart disease and we exclude ‘all cancers’ as this is a grouping of different diseases.

[10] ARCOS V 40-year trends of stroke incidence and outcomes in NZ, NISAN AUT July 2024 and Annual Aotearoa Stroke Reperfusion Report 2023 (data from the National Stroke Registry and Te Whatu Ora-Health NZ)

[11] NZ Health Survey 2022/23

[12] Social and Economic Cost of Stroke in New Zealand, 2020, NZIER

37% of people who experience stroke live with disability. For older people who experience stroke, many need costly residential care. For younger people returning home after stroke there are limited and sometimes no rehabilitation services available, particularly outside of metropolitan centres.

The lack of investment in community-based support services means people rely heavily on informal networks of family and friends and some resort to Give-a-little pages to raise money for private rehabilitation and to cover the cost of living. For those unable to return to work, stroke can cause significant financial hardship as disability from stroke is not covered by ACC.

Greater investment is needed by Government in the prevention of stroke and in increasing access to support services for people after stroke. The greatest rehabilitation gains are made in the first few weeks and months after stroke, so it is critical that appropriate supports are provided quickly, to increase the potential for people to live independently, and successfully return to work.

For those requiring a Needs Assessment Service Coordination (NASC), a more streamlined and nationally consistent approach is needed to minimise unwarranted variation. The assessment process should consider the neurological challenges (such as headaches, fatigue, memory loss and aphasia) facing people after stroke, which can impair their ability to provide the right information to get their full entitlements.

Motor Neurone Disease NZ

Motor Neurone Disease (MND) is the world's third most-common neurodegenerative disorder, after Alzheimer's and Parkinson's disease.[13] In New Zealand over 400 people are living with MND, on average, three people are diagnosed and two people die each week. While it affects adults of all ages the incidence is higher after the age of 50. MND (an umbrella term for 4-5 specific diseases) is a palliative diagnosis, with it being inevitably fatal within 20 to 60 months of diagnosis. Five to ten percent of people with MND live for ten years or more.

With rapid progression of MND it is imperative that people with MND and their families can access the right resources quickly across the care continuum. MND is clearly not an age-related disability and is usually a fast-moving, degenerative process that creates a need for urgency in diagnosis and assessment, and equal focus on reassessment and response as the person’s condition inevitably changes.

Brain Tumour Support NZ

An estimated 1100-1200 New Zealanders are diagnosed with a primary brain tumour each year. In addition, another 1100-1200 metastatic (secondary) brain tumours are diagnosed. Brain tumours can affect any age but more common in males, and people aged over 65 years.

Brain Tumour Support NZ was established five years ago in response to the severe lack of information and support for brain tumour patients and their families. There are gaps in publicly funded care in many areas and at many stages of the treatment pathway.

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[13] https://www.1news.co.nz/2018/06/17/nz-has-highest-rate-of-motor-neurone-disease-of-any-country-in-the-world/#:~:text=University%20of%20Auckland%20scientists%20found,2.8%20deaths%20per%20100%2C000%20people.

Many brain tumour patients lack access to neuro-rehabilitation services, following their surgery or radiation treatment. There is a lack of neuro-physiotherapists, occupational therapists, speech and language therapists, neuropsychologists, psychiatrists, and other allied health professionals to care for these patients under the public system. This forces patients to access treatment privately, which is unaffordable for many people.

There is a lack of dementia-level hospital care for terminal brain tumour patients who are nearing end-of-life stage and require high level hospital care. These patients are not eligible for long-term stays in the public hospitals and may not be eligible for hospice care as their life expectancy is not short enough. They are too sick to be cared for at home. The only option is for them to access care in private aged care facilities, at great cost. This option is unaffordable to many people.

Carer fatigue continues to have a real and devasting impact on people as they must often leave their jobs to support their loved ones, this impacts mental wellbeing and financial security.

The physical impact of caring for someone nearing end of life stage means that often physical wellbeing is impacted as lifting, supporting and the physical demands of caring for someone is not sustainable. There is no support for this.

The following story (abridged) has been provided Brain Tumour Support NZ and illustrates the system challenges for someone caring for their terminally ill partner.

> *Once a needs assessment is done it's hard to access the level of care needed e.g., we could get someone to help with showering, but they couldn't guarantee what time they could come and would only stay for 40 minutes.*
>
> *When respite care was needed, I needed to find a place myself. The staff had no idea of his needs … The staff didn't understand that his brain tumours meant he couldn't ask or ring them for help. More training is needed for carers to realize these patients have different needs than others in a hospital wing of a rest home.*
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> *I was told for him to stay after his respite time I had to buy a right to occupy room for either $140K or $200K. I refused to buy a room for him to die in. He wasn't there to retire, it felt so insulting to have buy a room.*
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> *We had to find another rest home hospital care as he had deteriorated, and I couldn't get the care I needed to take him home which was difficult.*
>
> *I had to pay for his care for the extra week needed to do this. I had to apply for a care allowance but because I had my Kiwisaver we were not eligible and had to pay his full $1600.00 weekly care costs. Terminal patients should not have to go through the same funding application process as those who are moving into a retirement village to retire. The spouse's KiwiSaver should not be included in the assessment, this is needed for their retirement.*

This enquiry needs to ensure there are sufficient community-based support services for people with brain tumours and improved access to quality palliative end of life care.

Multiple Sclerosis NZ (MSNZ)

Multiple Sclerosis is one of the most common causes of non-traumatic disability among young and middle-aged adults, the average age of diagnosis is 38. The number of people in Aotearoa New Zealand with MS is estimated to be 4,130 in 2021

Reports are indicating a growth in numbers in recent years, with more people being diagnosed. Comparatively in Australia, numbers of people with MS increased 30% between 2017 and 2021 and by 56.6% since 2010, a growth rate faster than population change. We expect NZ to demonstrate a similar growth pattern.

Due to the availability of high efficacy disease modifying therapies (DMTs), people with MS are living well for longer. However, MS is a chronic progressive condition with no cure, and 15% of those with MS are diagnosed with Primary Progressive MS (PPMS) from the outset.

People with MS often require some form of care or support. Care may include the use of in-home care support staff, full or part-time residential facility care, respite services, or in-home informal carers such as spouses or other family members. In many cases family members must reduce their working hours. Family carers of those with progressive forms of MS are also more likely to need respite support.

In 2021 MSNZ commissioned NZIER to undertake an Economic Burden Report.[14]. In New Zealand, the total contribution of MS informal care was estimated to be about three million hours per year. The total cost of MS informal care contribution was estimated to be $27.5 million for 2021.

NZIER calculated the total social cost associated with the prevalence of MS was estimated to be $266.3 million in 2021.

Moving into residential care is particularly difficult for those under 65 and not uncommon for people with more progressed MS. Often, due to lack of age-appropriate residential or respite services, they are required to stay in facilities for older persons. The mental health impact on those in this situation is extremely difficult. Due to the inadequate availability of residential care for the young people with disabilities and that includes people with MS, they are being placed in age care facilities which is both inappropriate for the young person with MS, but also blocks access for an older person who also needs residential care.

Keeping people out of residential or respite care by supporting community-based initiatives will have a positive impact not only on the mental health of people with MS but also reduce the financial burden on individuals, whānau and the wider economy.

Summary

The Government is focused on “achieving timely access to quality health care” (Government Policy Statement for (2024-27). The issues raised in this submission reflect the need for improvements across the care continuum in terms of timeliness, access, and quality of care.

Improving access to community-based services is particularly important for our members as most people with neurological conditions live at home for most of their time after diagnosis.

For those who are no longer able to live at home, access to residential /hospital level care needs to improve. This includes planning for increased demand as numbers of people with neurological conditions increase and developing flexibility within the system to provide age-appropriate care.

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[14] Due to the lack of available NZ data, the report used UK data (Kobelt et al. 2017) to identify the number of hours contributed by informal carer per month increased from 20 for a mild case to 150 hours for a severe case. On an annual basis, that is equivalent to between 240 hours and 1,800 hours of informal care, which is a substantial contribution from informal carers.

Ngā mihi nui

Rich Easton
Secretary Neurological Alliance and CEO Neurological Foundation of NZ

ALLIANCE MEMBERS

1. Alzheimers New Zealand https://alzheimers.org.nz/
2. Associated New Zealand Myalgic Encephalomyelitis (ME) Society https://anzmes.org.nz/
3. Brain Injury New Zealand https://www.brain-injury.nz/
4. Brain Tumour Support New Zealand https://www.braintumoursupport.org.nz/
5. Cerebral Palsy Society https://cerebralpalsy.org.nz/
6. Dementia New Zealand https://dementia.nz/
7. Dyspraxia Support Group https://dyspraxia.org.nz/
8. Duncan Foundation https://duncanfoundation.org/
9. Epilepsy New Zealand https://epilepsy.org.nz/
10. Huntington's Disease Association of New Zealand https://www.huntingtons.org.nz/
11. Migraine Foundation Aotearoa New Zealand https://www.migrainefoundation.org.nz/
12. Motor Neurone Disease New Zealand https://mnd.org.nz/
13. Multiple Sclerosis New Zealand https://www.msnz.org.nz/
14. Muscular Dystrophy Association of New Zealand https://www.mda.org.nz/
15. Neurological Foundation of New Zealand https://neurological.org.nz/
16. NZ Dystonia Patient Network https://www.dystonia.org.nz/
17. Parkinson's New Zealand https://www.parkinsons.org.nz/
18. Rare Disorders New Zealand https://www.raredisorders.org.nz/
19. Stroke Foundation of New Zealand https://www.stroke.org.nz/
20. Tuberous Sclerosis Complex New Zealand https://www.tsc.org.nz/